



CHEO Family Forum Member Champions Integration of CHEO and OCTC

Connor McHardy was all too familiar with the Children’s Hospital of Eastern Ontario (CHEO) and the Ottawa Children’s Treatment Centre (OCTC). Described by his mom, Mindy McHardy, as a “medically fragile and technology-dependent” child, he relied heavily on both organizations throughout his eight short years of life. OCTC focused on his physical and mental development, and CHEO on keeping him alive.

It’s because of the family’s extensive involvement with “these two fabulous organizations” – Mindy’s words – that Mindy and her husband, Geoff, are opinionated about the integration of OCTC and CHEO and the benefits it promises other parents and families.

“Although Connor’s outcome would not have been any different if there was a single organization, my own experience certainly would have been,” she says. “The pressure on you, as a parent, to bridge two organizations – and to essentially be the glue that holds everything together – is overwhelming, especially when your child is struggling in every aspect of life.”

A struggle from birth

Six hours after Connor was born at the Ottawa Hospital (General Campus) in April 2004, he was transferred to the Intensive Care Unit at CHEO, and two days later underwent open heart surgery, a procedure he would need again five months later.

“The surgery saved his life and we thought everything was fine,” says Mindy, who had learned a week earlier that Connor had a heart condition and would need surgery soon after birth. “Little did we know that we were entering a whole new territory.”

In his first few months of life, Connor experienced a number of acute life-threatening events, when six to eight times a day he would go into unexplained cardiac arrest – events that ultimately led to his second open heart surgery. A paralyzed vocal cord meant from Day 1 he received nutrients and fluids through a gastrointestinal tube. And, by nine months, he was on oxygen 100 percent of the time.

About the same time, it became clear Connor wasn't developing at the rate he should be, and he was referred to a developmental pediatrician at OCTC, the start of a back and forth journey between clinics and specialists at OCTC and CHEO. The pediatrician diagnosed him with Autism and referred him to CHEO's Autism program. While waiting to access that service, he began preschool at OCTC.

Orthopedics was another area with crossovers between CHEO and OCTC. "The doctor we saw at CHEO for scoliosis was the same doctor we saw at OCTC for AFO (ankle-foot orthosis), but because scoliosis and AFO are handled by different organizations, we had to book separate appointments."

From 2004 to 2012, more than 15 different medical practitioners from across OCTC and CHEO were involved in Connor's care. From CHEO, there were one or more of each of the following (depending on whether he was an inpatient or outpatient): cardiologists, respirologists, nephrologists, psychiatrists, neurologists, geneticists, gastroenterologists, urologists, ophthalmologists, and ear, nose, and throat specialists. From OCTC, there was a developmental pediatrician, infant development physician, psychiatrist, social worker, and speech therapist. And, from both, there were occupational therapists, physical therapists and dieticians. In between seeing specialists and going to clinics, Connor was admitted to CHEO many times for acute life-threatening events.

"When we were in CHEO's care during Connor's first year and seeing doctors as an inpatient or outpatient, we had a sense of security because we were part of the system. Then when you are told your child has developmental issues and now has to start seeing specialists in another organization, it's stressful. What if the new organization isn't as good? What if they aren't as knowledgeable? What if? What if?"

Mindy found that OCTC was also good, very good, but at the end of the day it was a different organization, even though it was co-located with CHEO on the Smyth Road medical campus.

"You have a team of specialists focused on helping your son, which is wonderful, but the problem is that your team is across two different organizations. They are separate administrations, with separate medical records. I was always afraid I was going to forget to tell somebody something – so there was a lot of stress trying to manage so many specialists for a child who didn't follow any textbook and from whom you learned to expect the unexpected."

Connor, who was the size of a two year old when he passed away at age eight, was indeed more than his medical chart. Mindy describes him as a little boy who lived every day to its fullest, facing each challenge head on and "blowing through them" with determination and an indomitable will. Although connected to an oxygen tank, he was mobile and could often be seen walking or running – and always laughing or smiling – with 50 feet of tubing behind him. Although he didn't speak, he learned more than 400 words and used a picture communications system on his iPad to communicate his wants. He would often select the icon for *The Backyardigans*, his favourite TV show. In addition to OCTC preschool, he went to a public school for one term, and loved every minute of it. He also attended OCTC summer camps and went to Disney World twice, once as the beneficiary of the Children's Wish Foundation.

"We didn't have a diagnosis and had no idea when our son's journey would end. The constant uncertainty was exhausting but it was Connor's joy and happiness that kept us going. Our focus was to help Connor live his best life – for however long that life would be – in spite of his differences. And we relied heavily on the medical profession – including OCTC and CHEO – to help us do that.

“If those two powerhouses were together as one, I know I would have felt so much better. There would have been much less fragmentation and less stress on me trying to keep everything together.”

Connor passed away peacefully in the arms of Mindy and Geoff at Roger’s House, February 29, 2012, only 15 minutes into the leap year. His journey with CHEO, however, is not over. His geneticists, who believe he may have a yet-to-be discovered syndrome, have included his DNA in the nationwide Care for Rare study that CHEO is leading. The study could discover Connor’s syndrome and others suffering from it, as well as potential treatments.

Mindy, too, is continuing her own journey with both CHEO and OCTC. She is the CHEO Family Forum executive member responsible for communications and is the acting chair of Roger’s House Family Advisory Council. She was also a family representative on the Ottawa Special Needs Strategy table for Coordinated Service Planning and Integrated Rehab, which was co-chaired by CHEO and OCTC. And, most recently, she was one of the parent voices on the OCTC-CHEO Joint Alliance Task Force that was established by the Boards of both organizations to make recommendations related to the integration of OCTC and CHEO.
